Epilepsy12 – patient/carer perspective
SDM
18 06 21

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Background and context

- Who we asked
  - Epilepsy Action
  - C & YP forum
- Who we've spoken to
  - Three parents
  - One YP
- Other resources
  - The Epilepsy Space
  - NHS RightCare

What we asked about

- Main areas of concern
- Greatest benefits
- Areas for improvement
- Transitioning
- Outputs

Main areas of concern

- Lack of understanding in society
- Inconsistent care from GP's with insufficient knowledge
- Not enough time with consultants
- More information available at the beginning
- Mental health and safety of your child.
- Side effects of the medication

Greatest benefit

- Access to specialist nurses
- Mental health support/counselling
- Timely referrals
- Joint working with other specialists
- More information about child’s learning
- Basic information available from the beginning

Transitioning

- Preparing families
- Continuity of support for carers
- More information for Inclusion and Disability departments in work and educational settings
- Mental health and emotional well-being
- Pregnancy
- Support groups for YP

Areas for improvement

- More publicity to raise awareness
  - Schools
  - Further education settings
  - Within communities
- Misdiagnosis
- Better support for people with learning disabilities and epilepsy

Rightcare Epilepsy Toolkit

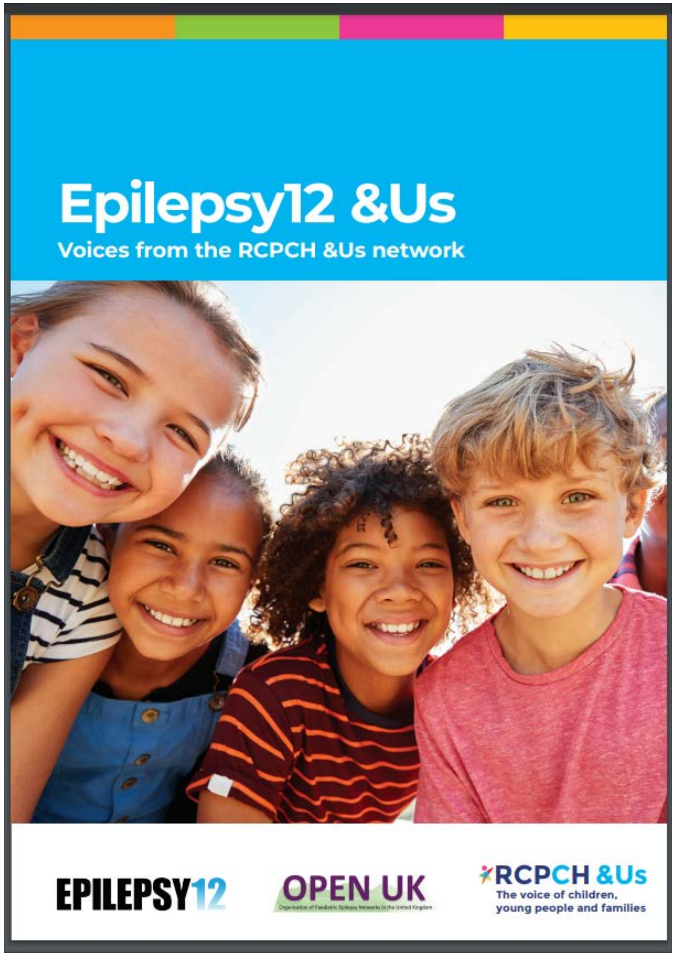
System improvement priorities

- Identification and segmentation of epilepsy population
- Misdiagnosis
- Taking a risk management approach to mortality
- Access to epilepsy specific services
- Support for specific patient groups
- Mental health and emotional wellbeing support
- System-wide education and training on epilepsy
- Medicines optimisation
- Coordination of care
- Personalised care
- Experience of care
- Self-assessment questionnaire

NICE **Young Epilepsy** **SUDEP** **Epilepsy Action**

Outputs

- Positive – “the layout and usefulness are excellent” “easy to understand”
- “more visual representations of the data/findings would be great”
- “how can it help me get better care for my child”
- “I think it’s hard as a parent to understand how this can be applied practically”



Epilepsy12 &Us

Voices from the RCPCH &Us network

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The voice of children, young people and families